

LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

QUESTION: "Who's in charge? In our group, some of the spouses have taken over the leadership roles and they are not as understanding of our situation. Has this happened to other groups? How was it rectified?"

ANSWER: Who do you want to be in charge?

I have this theory that I read about years ago and have seen many times since, and it is this: WE ALL DO WHAT WE WANT TO DO. I know right off, some folks are beginning to argue—coming up with their first excuses to invalidate this hypothesis. Give it some time.

When I was a kid—I don't know, maybe five years old—my dad took my older brothers and me to Mandy's Café in our home town for ice cream one afternoon. As we sat in our booth waiting for the waitress, he asked each of us what flavor we wanted. Joe wanted chocolate. Bill chose strawberry. When it came my turn, I said, "I don't care."

"Well then," my dad replied, "If you don't care, you don't get any ice cream."

Yes, yes, I can almost hear it now—a few readers saying, "What a mean ol' guy he was!" Keep reading.

Truth is, my dad taught me something extremely valuable that day. I learned to care—about me, about what is important to me—and he taught me to speak up, to express myself, and to be sure what I'm saying is what I mean.

So we all do what we want to do. Thing is, we're likely to trick ourselves if we aren't honest about what we want. At the moment my dad asked me that question, I wasn't thinking through the consequences. I was aiming at the wrong target. Surely when I said what I said, it hadn't occurred to me that my desire to act coy or humble actually didn't begin to approach my desire for a big bowl of chocolate ice cream.

Or maybe I had in my subconscious that I could pull off both—was there a way to parlay being a demure sweetie into getting that chocolate ice cream? Somehow grab a frozen goodie without actually appearing to want it? Or maybe toss a little sympathy into the mix—convince my dad I believed "poor, pitiful me" was so unworthy that just any flavor would do, and shoot for a compensating two scoops? Or win the bonus prize of being begged to choose a flavor? Clearly I didn't want to eat ice cream nearly as much as I wanted to play games.

Knowing what we want is important. And how to stand up for ourselves, how to take charge of our lives. This is especially true for polio survivors—it's too easy for people to see those of us with disabilities as individuals whose choices others should make.

Of course polio support groups should be run by the polio survivors who come for support. Otherwise they're not polio support groups. We members should be talking about our own problems and finding our own solutions—running our own meetings and doing our own thing.

Spouses have a need, as well. Most spouses are interested in how best to understand what PPS means to a loved one immersed in this new polio dilemma and how best to help. Because of this, it seems a healthy thing for spouses to sit in on polio meetings, if they like, to find out what's going on. Additionally, certain spouses find themselves requiring their own support group, figuring out how to tackle these changes in their lives, talking about what's happening to them.

There can't be much benefit to allowing spouses to control the direction of the discussions and activities of a polio support group. It may feel easier at first to "let George do it." But much as he wants to assist the one he loves, George can't do it—he's not a polio survivor and will never have the heart and mind of a polio survivor. Maybe the best help George can provide is to encourage the independence polio survivors strive for. (Oh yes—and carry a few boxes.)

Now, if it's true that we all do what we want to do (and I'm sticking with this), then groups have to decide what they want. If they want to be in charge and, instead, spouses have taken over, members will step forward, thank the spouses for their kindness and dedication to the group, and assert they are ready to do the job themselves now. They will then do exactly that.
